



# Heart OBServation app: development of a decision support tool for parents of infants with severe cardiac disease


## Original Article

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### Abstract

*Background and objectives:* Many parents of infants with CHD find it difficult to recognise symptoms of deterioration in their children. Therefore, a personalised decision support application for parents has been developed. This application aims to increase parents' awareness of their infant's normal condition, help them assess signs of deterioration, decide who and when to contact health services, and what to report. The aim of this paper is to describe the concept and report results from a usability study. *Methods:* An interprofessional group developed a mobile application called the Heart OBServation app in close collaboration with parents using an iterative process. We performed a usability study consisting of semi-structured interviews of 10 families at discharge and after one month and arranged two focus group interviews with nurses caring for these families. A thematic framework analysis of the interviews explored the usability of features in the application. Usability was assessed twice using the System Usability Scale, and a user log was registered throughout the study. *Results:* The overall system usability score, 82.3 after discharge and 81.7 after one month, indicates good system usability. The features of Heart OBServation were perceived as useful to provide tailored information, increase awareness of the child's normal condition, and to guide parents in what to look for. To empower parents, an interactive discharge checklist was added. *Conclusions:* The Heart OBServation demonstrated good usability and was well received by parents and nurses. Feasibility and benefits of this application in clinical practice will be investigated in further studies

An estimated 500–600 children are born with CHD in Norway each year. Approximately 25% of them have severe defects and require early diagnosis and treatment.<sup>1</sup> CHD is still a major cause of infant death, and approximately 10% of Norwegian children with severe heart disease die during the first two years of life.<sup>2</sup> Recent research shows that 29% of these deaths occurred unexpectedly outside of/unrelated to surgery, 60% of which after gradual deterioration at home.<sup>3</sup> Many parents find it difficult to recognise worsening symptoms in their children. They also struggle to describe the physiological and behavioural changes that occur and decide what action to take.<sup>4</sup>

In Britain, an expert group suggested actions to improve services and reduce adverse events after discharge. They recommended education and training of parents before discharge, clear guidance to families and health professionals on “what is normal” for that child as well as signs and symptoms to look for and how to respond to them, and the distribution of important contact numbers. They also recommend early warning tools that should be nationally standardised to improve navigation of the complex services pathway.<sup>5</sup>

To support parents' ability to perform their new caregiving responsibilities and detect deterioration after discharge, comprehensive interstage home monitoring programmes have been developed for parents of infants with single ventricle.<sup>6,7</sup> Such programmes use combinations of written material, films, and digital solutions that aims to educate parents, support the health professionals teaching them, and offer tools for detecting deterioration. Some of these programmes exchange data digitally with healthcare teams. In Norway today, the population of infants with single ventricle is small, but recent data show that other infants with CHD also are in need of supportive initiatives.<sup>3</sup> In addition, strategies to support parents at home must be compatible with existing health services.

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Based on these challenges for parents, one of our project group members suggested the concept of a digital tool for decision support in 2018. A multidisciplinary team further developed this concept. Hence, this article aims to describe the development and usability of a personalised application for mobile phones that seeks to interactively increase parents' awareness of their infant's normal (habitual) condition, help them recognise signs of deterioration, and help decide who and when to contact for help.

## Materials and methods

An interdisciplinary group from Oslo University Hospital developed the Heart OBServation app to support parents of infants with severe CHD. This group of infants includes a large clinical spectrum. Some infants require extensive monitoring at home, whereas others can be managed through parental care.

### Development of intervention

The Heart OBServation app was developed using an iterative systematic evaluation process (Fig 1). It included a combination of: 1) exploration and stakeholder involvement; 2) literature review and theoretical conceptualisation; 3) development of features and content; 4) study of features' usability; and 5) revision of HOBS, incorporating this study's findings.

### Exploration and stakeholder involvement

The initial goal was to reduce stress and mortality by providing parents with a decision support tool. This idea was presented using paper prototypes to the Norwegian Association for Children with Congenital Heart Disease, health professionals at the Department of Pediatric Cardiology, and Neonatal Intensive Care Unit at Oslo University Hospital. Users and medical professionals endorsed this concept and the clinic formally approved it. We established a multidisciplinary and user-centred project group to guide the development of content and features in the application. To ensure that the user perspective was captured, the mother of a child with CHD participated in the development process throughout the project. The chief adviser in the Norwegian Association for Children with CHD provided additional contact with parents for feedback during the development process. To ensure a flexible and intuitive system of features, we included a user experience designer. Through an iterative process of exploration and stakeholder involvement, one test group included six parents of children with CHD and four test groups consisted of 28 nurses and two neonatologists from the neonatal ICU. The patients installed a prototype of the mobile application, completed tasks using a questionnaire, and provided written and oral feedback about the features. Following revision based on this feedback, four parents of infants with CHD hospitalised in the neonatal ICU used a test phone for one day, which also gave us valuable feedback.

### Literature review and theoretical conceptualisation

During the iterative development process, we explored two main theoretical perspectives on how to build supportive features in the application. The application was initially intended as a decision support tool. Such tools usually include a combination of general and individual health information to support decisions regarding patients' health. They can advise users if something is normal, show information relevant to the problem, and recommend actions based on an algorithm.<sup>8</sup> Infants with CHD are vulnerable, and their symptoms may be subtle and similar to

normal physiological and developmental variations. Hence, we acknowledge the risk of providing clear recommendations of actions based on an algorithm. With the educational goals in mind and to prevent incorrect decisions, we designed the application as an educational tool. HOBS suggests which signs to look for, how parents could assess them, and when to contact health professionals based on their own interpretations.<sup>9</sup> Since no automated recommendations are made, the HOBS app does not qualify as a medical software device.<sup>10</sup>

Developing the application as a capability-enhancing decision support tool raised the importance of including features to support discharge preparation and readiness. Parents in the target group for HOBS were in transition from hospital to home care for infants with CHD. Readiness for discharge includes competence managing self-care at home, receiving adequate support to cope with life after leaving the hospital, the psychological ability to manage the process, and adequate information and knowledge to respond to common problems.<sup>11</sup> To promote competence managing the infant's care, available support and adequate knowledge were within the scope of the application and intertwined in the features.

### Development of features and content

After the initial development phase, we decided to include the following six features:

**My Child.** In this feature, parents in collaboration with health professionals register information about their child's birth (weight and date), diagnosis, treatment, and needs after discharge, including surgery, pathophysiology, nutritional demands, medications, and need for health-related equipment. The application uses this information to individualise observations in "Normal for my child", questions in the "Assessment function", and to adapt personalised "Information" (Fig 2, Image 1, upper square). A list of tasks to be completed before discharge is included in this section to ensure the completion of settings and guidance of use.

**Normal for my child.** This feature is built upon the concept that awareness of the infant's normal condition enhances the recognition of signs of deterioration.<sup>5</sup> The consequences of CHD vary, and the "normal" status must be personalised.<sup>12</sup> Hence, in this feature, parents select their infant's condition and behaviour from pre-determined alternative descriptions of respiration, circulation, elimination, nutrition, sleeping, and satisfaction. There are 6–10 categories depending on the surgical procedures and monitoring equipment. In each category, parents choose from a list of options that best matches their child. The healthiest choice is at the top of the list, making symptoms of deterioration comprehensible (Fig 2, Images 1 and 2). Parents add concrete numbers for oxygen saturation, respiratory rate, and heart rate.

**Information.** Individualised information based on the settings from "My child" is allocated to a reading list. The list contains links to nationally approved information for parents, developed by cardiologists and other healthcare professionals working with infants with CHD. This feature aims to support parents in managing self-care at home and responding to common problems<sup>11</sup> (Fig 2, Image 3).

**Contact.** Telephone numbers to the national centre at Oslo University Hospital are listed in this feature. Information about who and when to call on different occasions is explained, and parents can call directly from the application (Fig 2, Image 4).

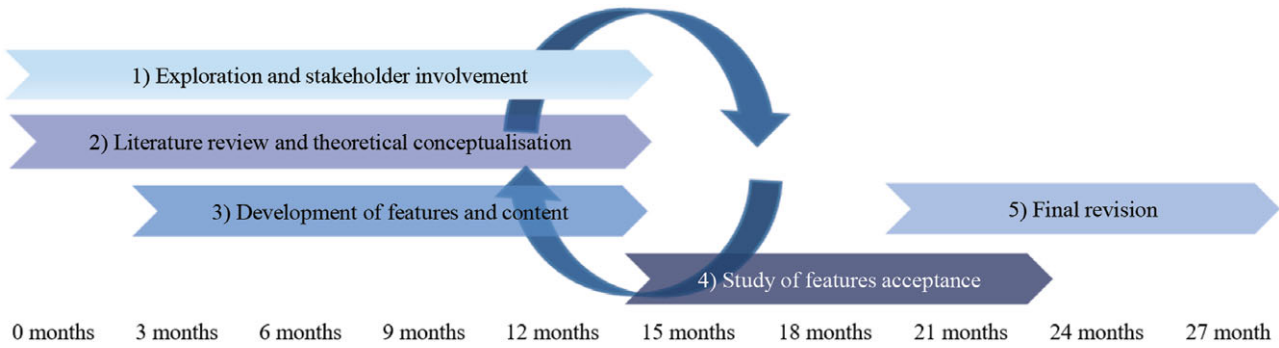


Figure 1. Iterative stages in the development of the Heart OBServation (HOBS) app.

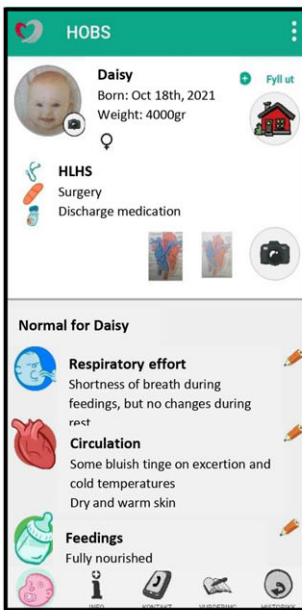


Image 1. «My Child»

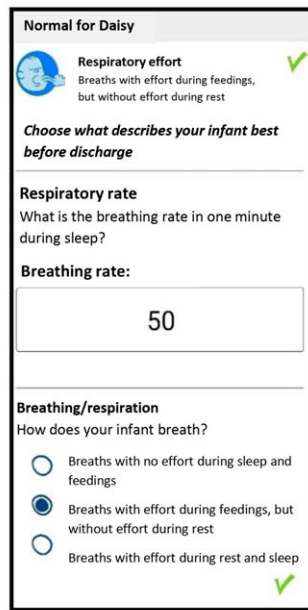


Image 2. «Normal for my child»

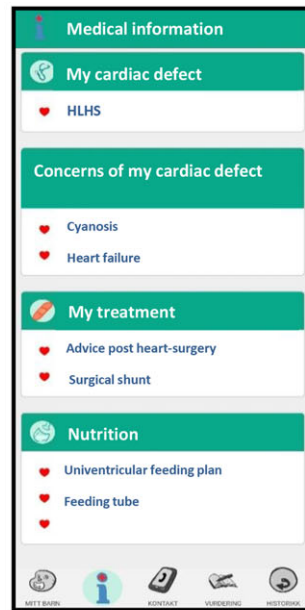


Image 3. «Information»

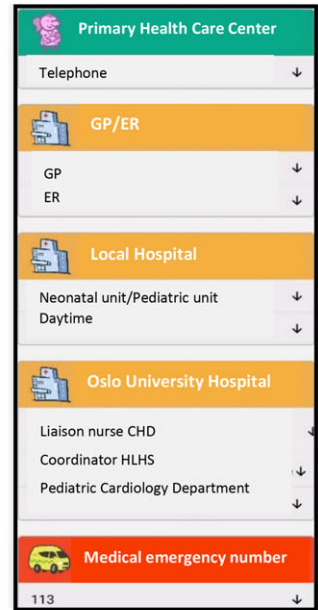


Image 4. «Contact»

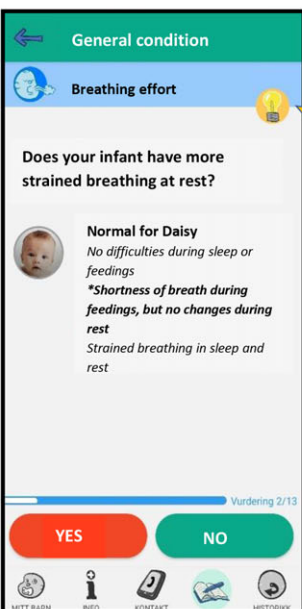


Image 5a. «Assessment»

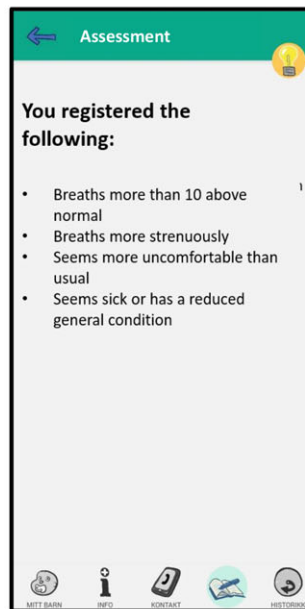


Image 5b. «Assessment respons»

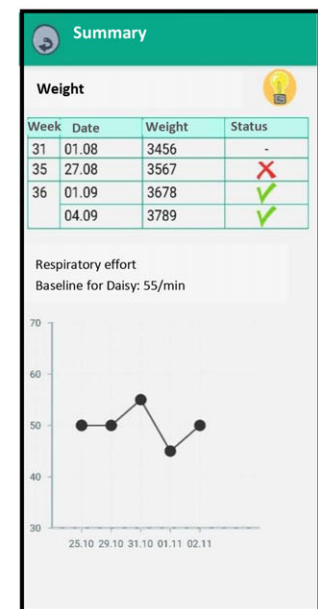


Image 6. «Summary»

Figure 2. Features in Heart OBServation app (HOBS).



When the infant is ready for discharge, parents should register the allocated telephone numbers to local health services before leaving the hospital.<sup>11</sup>

**Assessment of my child.** The assessment feature covers knowledge to support what to look for.<sup>5</sup> It consists of three areas.

- 1) *The general condition* was based on the normal condition of the infant. Based on the settings, parents receive 7–14 questions. The selection of questions includes measures from the paediatric early warning score and more specific symptoms of deterioration in infants with CHD.<sup>4,13</sup> Parents assess respiration, circulation, elimination, eating, sleeping, satisfaction, and well-being. They answer “yes” or “no” to questions about deterioration, and a tip-button (light bulb) may instruct them on how to do it, how to interpret the result, and what to do (Fig 2, Image 5a). At the end of the assessment, they receive a summary of worsening symptoms and a general advice to contact healthcare professionals if they are still uncertain or uncomfortable (Fig 2, Image 5b).
- 2) *Wound assessment:* Parents may take and save pictures of wounds or other visual objects of interest they want to follow. The tip button provides advice about signs of infection.
- 3) *Weight registration and other measurements:* Weight may be plotted, and weight gain is calculated as sufficient or not visualised by a red cross or a green tick in the summary function.

**Summary.** The Summary feature provides an overview of completed assessments. Previous assessments of the infants’ conditions are presented as bar charts, and other measurements are presented as curves (Fig 2, Image 6). This function provides an overview and may support communication with health professionals during consultation and follow-up.

#### Legal aspects

The Information Security Department at the Oslo University Hospital approved the data protection impact assessment and risk analysis of the application for privacy considerations and information security.

#### Study of features’ usability

After the initial development, we examined the experiences of HOBS features among parents and nurses in a usability study

**Study intervention procedure.** The eligibility criteria for participation among the parents were that they owned a smartphone, were parenting an infant hospitalised with severe CHD at Oslo University Hospital, gestational age above 34 weeks, and had appropriate Norwegian communication skills. We recruited families after the infant’s cardiac surgery or the final diagnosis if no intervention was conducted before discharge. They signed a written consent. Parents got the Heart OBServation app on their own phones and received a 10–15-min introduction of its main features. Because infants with CHD varies in severity and need of monitoring, each family was advised to make assessments until they were confident in what to look for, before consultations and if they felt unsure of the infant’s condition. An electronic reminder in the hospital’s electronic system for monitoring and ordinations popped up twice a day for the nurses to ensure continuation of guidance before discharge. A checklist of nursing tasks to prepare parents for discharge was attached to the patient’s binder.

Nurses who engaged in family guidance and patient care received a 20-min lecture on the purpose and use of Heart OBServation, its

features, and the tasks to complete together with the families. They were encouraged to consult the e-learning course on how to guide the parents and other resources available on the Heart OBServation website, established to support health professionals nationwide ([www.hobs.no](http://www.hobs.no)). A test phone with the application was also available in the unit to make nurses confident with the Heart OBServation app features and content.

**Semi-Structured parent interviews.** Parents participated in two semi-structured interviews via phone: at the time of discharge from OUH and one month later. The researcher followed a semi-structured interview protocol. The topics in the interviews at discharge were questions about app features and functionality or any other comments. The second interview focused on the usability of the Heart OBServation app features and change requests.

**System usability and system use.** After both interviews, the System Usability Scale was sent electronically to the parents to measure system usability of the Heart OBServation app.<sup>14</sup> The instrument gives a general score of system usability and consists of 10 items, with five response options from *strongly disagree* to *strongly agree*. Total scores range from 0 to 100, with 100 indicating the most positive response.

In addition, we collected system user logs to capture the use of the assessment function and information links.

**Focus group interviews with nurses.** Eight nurses from three departments that followed the families in the study were recruited to two focus group interviews after the last family had completed their participation. Their work experience was 1–35 years. The moderator followed a semi-structured interview guide and used a PowerPoint presentation of the Heart OBServation app features to refresh memories and avoid misconceptions. Each feature was discussed, and requests for additions and changes were encouraged. An observer noted the ambiguity and wrapped up the discussion to clarify the interpretations.

**Deductive framework analysis.** A deductive framework analysis was used to evaluate the features of the application.<sup>15</sup> Comments were sorted as they related to the Heart OBServation app features: 1) my child, 2) normal for my child, 3) measure of condition, 4) wound observation, 5) weight, 6) information, 7) summary, 8) contact, and 9) overall impression. Comments about each feature were interpreted, discussed, and condensed into a meaningful unit representing the patients’ views. Initially, we analysed data from parents and nurses separately. Next, we merged the data sets and compared them to determine the necessary revisions to the Heart OBServation app. Finally, all data in the framework was analysed to explore ideas for new features and changes to the existing design.

## Results

### Patients of the usability study

Eleven families were consecutively included over a period of three months. One infant recovered before discharge, and one family did not respond to phone calls or questionnaires and did not use the application after hospital discharge (Table 1). The diagnoses represented among the infants were “tetralogy of Fallot”, “Ebstein anomaly”, “aortic stenosis”, “coarctation of the aorta”, “interrupted aortic arch”, and “truncus arteriosus”. For more demographic information regarding the parents and infants, see Table 1. All infants

attended follow-up after discharge, and no adverse events occurred during the study.

### Results regarding system usability and system use

The overall system usability scores after discharge were 82.3 and 81.7 after one month, indicating good system usability (70–100).<sup>16</sup>

Five parents used the assessment function to evaluate whether they should contact health professionals or not. Only one parent made contact and that was related to observation of increased respiratory distress. The amount of assessment varied depending on CHD severity and cardiologist recommendations. Each parent entered 2–9 different information links (median, 6), but many of the links were entered several times, with a peak at the beginning of the study (Table 1). The most frequently used link was about the infant's diagnosis, postoperative care, and consequences of the infant's condition. Users overlooked the possibility of reading extended information in additional tabs within the allocated information.

### Semi-Structured interviews and focus groups

Both parents were invited to participate in semi-structured interviews, but only three fathers joined after discharge from Oslo University Hospital and two after one month at home. The first interview lasted for a mean 12 min (range, 7–14 min). Five of these interviews occurred when the child was still at a local hospital and four when they were at home. The second interview lasted for a mean 18 min (range, 10–26 min). The focus group interviews with nurses lasted for 75 and 90 minutes.

The Heart OBServation features were considered as intuitive and easy to use. Users found the contents and features valid and the information relevant, available, and easy to understand. They requested only minor revisions to the features and content. Table 2 presents an overview of the results after the framework analysis, illustrating quotes regarding each feature

### Final revision of the Heart OBServation app

Overall, the results from the qualitative analysis, System Usability Scale, and log data provided useful information for the revision of Heart OBServation. The project group held digital workshops to review, select, and decide on revisions. The final revisions included nuance some categories in “normal to my child”, more explicit advice in some areas of “the assessment feature”, add an interactive discharge preparation list, and redesign “the information feature” to be more personalised. See Table 2 for details of the requested and fulfilled revisions.

## Discussion

In this paper, we report on the process of development, usability testing, and revision of a smartphone application to support the parents of infants with severe CHD as an alternative to traditional paper-based information. The results of this usability study are promising, as the usability scores were high, and the parents and nurses evaluated Heart OBServation baby as easy to use. Users considered the content and features valid and requested only minor revisions. Interviews with parents and nurses provided useful information about their use of the application and necessary revisions.

An important aim of the Heart OBServation application was to help parents know what was normal for their child and use it as a

baseline for assessments.<sup>5</sup> Parents and nurses expressed that the use of Heart OBServation drew attention to and provided control over something parents would normally have been less aware of. Choosing between defined categories does not precisely describe the infant's condition, but the added nuances may refine the parents' apprehension about their child. The parents did not express any problems when assessing changes from their registered normal condition. Our interpretation is that the personalised design facilitated the parents' awareness of “what is normal” versus not.<sup>5</sup>

Support for discharge preparation is an important aim of the Heart OBServation app. The existing discharge checklist for the application was neither interactive nor personalised, and nurses were unsure about parents' ability to execute the right initial settings by themselves. To agree on completion of learning tasks is important for the empowerment of parents and discharge preparations.<sup>11</sup> Such empowerment has been facilitated in programmes to support parents of infants with single ventricle in home monitoring programmes.<sup>17</sup> Hence, an interactive discharge feature for parents based on personalised settings in “My child” to confirm readiness for discharge was included and advanced underneath the home icon.

Parents evaluated the information function as relevant, available, and easy to understand. Further investigations revealed that some information headings were general, and user logs revealed that tabs used to explore additional electronic information were overlooked. Hence, we revised the information feature to use a more personalised design and removed the tabs to obtain hidden information.

Requests for new functionality, such as sharing information and settings between parents, were not included because of financial limitations and data privacy matters. We also rejected the request of a calendar in Heart OBServation to track events and consultations because this function is available on all mobile phones.

For unknown reasons, one family did not use the application after discharge. As mentioned by a nurse in one of the focus groups, this could relate to the fact that parents not necessarily appreciate mobile applications, or it might be overwhelming to capture in a chaotic situation.<sup>18</sup> We do not know whether paper information and contact with health professionals would have been preferred in this case. However, the availability of information in a mobile app may be beneficial to all parents as experienced by parents and nurses in this study. An ongoing study will compare whether Heart OBServation or written information is preferred in discharge preparation and follow-up.

Fathers participated in only five of the 17 interviews. Nevertheless, these fathers were positive about the features of the application. Reasons for limited participation may have been that mothers are still primary caregivers on paid leave, hospitals' coronavirus disease 2019 precautions and visit restrictions disfavoured fathers, and fathers had started working by the time of the second interview. In this situation, the possibility of sharing content could have been favourable to utilise Heart OBServation for both parents.

There are limitations to the present work related to the short trial period and small number of patients. One of the aims of the application is to empower parents to recognise deterioration in their children. Although many parents acknowledged the benefit of having a checklist of symptoms to look for, only one family experienced deterioration during the trial period, which is not enough

**Table 1.** Parent and infant demographics, clinical characteristics, and user logs (n = 9)

| Characteristics  | n (%)   | Median | Max  | Min  |
|--|---------|--------|------|------|
| Main caregiver first month                             |         |        |      |      |
| Mother   | 9 (100) |        |      |      |
| Main caregiver age                                     |         | 31     | 38   | 27   |
| Years of education after mandatory school              |         | 7      | 9    | 3    |
| Families with siblings                                 | 6 (67)  | 1      | 4    | 1    |
| Single parents   | 1 (11)  |        |      |      |
| Infant birth and medical information                   |         |        |      |      |
| Gestational age  |         | 39.3   | 40.6 | 37.2 |
| Female   | 2 (22)  |        |      |      |
| Male   | 7 (78)  |        |      |      |
| Antenatal diagnosis                                    | 2 (22)  |        |      |      |
| Postnatal diagnosis                                    | 6 (67)  |        |      |      |
| Post-discharge diagnosis                               | 1 (11)  |        |      |      |
| Surgery  | 6 (67)  |        |      |      |
| Catheterisation  | 2 (22)  |        |      |      |
| Waiting for surgery                                    | 4 (44)  |        |      |      |
| Medical treatment after discharge                      | 4 (44)  |        |      |      |
| Hospital stay  |         |        |      |      |
| Total days of admission at specialist centre           |         | 12     | 21   | 7    |
| Days with HOBS before discharge from specialist centre |         | 6      | 9    | 2    |
| Days at local hospital before discharge                | 5 (56)  | 1      | 7    | 0    |
| Consultations with liaison nurse                       | 8 (89)  | 2      | 3    | 0    |
| Consultations psychologist                             | 7 (78)  | 2      | 3    | 0    |
| Follow-up after discharge                              |         |        |      |      |
| Days of follow-up from local hospital after discharge  | 4 (44)  | 0      | 21   | 0    |
| Consultations with cardiologist after discharge        | 9 (100) | 2      | 4    | 2    |
| Consultations with community nurse                     | 9 (100) | 3      | 4    | 2    |
| Days from discharge to second interview                |         | 38     | 44   | 30   |
| Type of smartphone                                     |         |        |      |      |
| Apple  | 7 (78)  |        |      |      |
| Android  | 2 (22)  |        |      |      |
| Log from app   |         |        |      |      |
| Number of assessments to practice at hospital          | 8 (89)  | 1      | 2    | 0    |
| Number of assessments at home                          | 9 (100) | 2      | 7    | 1    |
| Entered information links                              | 9 (100) | 6      | 9    | 2    |

to claim that Heart OBServation increases their capability to recognise and act on possible deteriorations. On the other hand, half of the included families used the assessment function when managing uncertainty of symptoms like crying and vomiting and felt reassured and did not contact healthcare professionals. This reassurance could be a potential benefit.

## Conclusion

This study is the first to evaluate usability of features in a mobile application, to support parents to infants with a broad spectrum of severe CHD diagnosis. The Heart OBServation app combines new and already established strategies to prepare and support parents with severe CHD in one interactive application. This application

**Table 2.** Results from deductive analysis of parents' and nurses' experiences of the functionality of the heart OBServation (HOBS) app

| Feature and description   | Extract from parental evaluation of the features  | Illustrating quotes from parents  | Extract from nurses' evaluation of features  | Illustrating quotes from nurses  | Changes   |
|---|---|---|--|--|---|
| <b>My child:</b> Individualise HOBS to the infant regarding diagnosis, treatment, needs, and birth information. Controls settings in normal for my child, assessment of condition, and information.   | <b>Experiences:</b> Easy and intuitive to fill out. Wants introduction and support to secure correctly filled out.<br><b>Requests:</b> None.  | "We (with a nurse) kind of went through it again and adapted it completely, so I think it was very easy" Mother (M)3  | <b>Experiences:</b> Clear, simple, and comprehensive. Entail guidance to choose the right topics.<br><b>Requests:</b> None.  | "I think it is quick and specific on what is important" Nurse (N)4<br>"I would not trust parents to do it (settings) on their own" N3  | Include completion of app settings in discharge function.                               |
| <b>Normal for my child:</b> Infant's appearance is selected by parents regarding, respiration, circulation, elimination, eating, sleeping, and satisfaction.  | <b>Experiences:</b> Easy and intuitive to fill out. Raises awareness of child's normal appearance.<br><b>Requests:</b> Nuance some categories (vomiting, eating habits, and clammy skin).   | "It was very easy to fill in, but I might wish it was a little more options" M6<br>"It varies during the day... He gets hot and humid sometimes, but other times he is dry and hot" M3<br>"... I feel confident about her normal condition"... "I might not have such control without it (HOBS)" M9   | <b>Experiences:</b> Gives systematic, specific overview to required observations. Focuses on respirations and circulation, which parents usually do not pay attention to. Enables a retrospective view of what was normal for the child.<br><b>Requests:</b> Video of respiratory distress should be included. More nuanced categories in eating, skin appearance, and vomiting. | "It is much more systematic"...<br>"It was not presented in such a way before and to be able to go back" N3<br>"But I think it's the two on top (respiration and circulation) that we care about a lot, and the next two that parents would like to talk about. Because it is nutrition they are very concerned about" N2<br>"I think that with video, parents can more easily assess normal respiration for their child" N1 | Video of respiratory distress is included as a link.<br>Nuance three categories.        |
| <b>Assessment of condition:</b> Parents record respirations, circulation, elimination, eating, sleeping, and satisfaction due to an algorithm. They answer yes or no to questions about deterioration and a tip button may advise them how to do it, how to interpret the result, and what to do. | <b>Experiences:</b> Nice to have as a checklist if needed. Gives awareness of what to look for and what it means. Not necessary to use it every time because they remember. It might be stressful to know that normal changes like increase of crying and vomiting may imply deterioration.<br><b>Requests:</b> Clear description of interpretation of what to do about negative measures of increased vomiting and crying. | "I am thinking... it's just an extra reminder of what I should follow and be aware of" M8<br>"... I think they (the advice) are great. Very simple and informative. Very soothing really because it's kind of eerie" M6<br>"The assessment part I think is quite despairing at times because it is a question of whether the child cries more than usual... I then think that it is something with the heart right away" M4 | <b>Experiences:</b> Clarifies what to look for in a list. Useful as a tool to learn what to look for and how to do it.<br><b>Requests:</b> None.   | "It becomes very clear when you are going to assess your child" -<br>"You should look after these things!" N5<br>"And it's easier to assess the baby with the app, and the parents might think so too" N1  | Include completion of teaching about interpretation of measure in a discharge function. |
| <b>Wound observation:</b> Parents may take pictures of wounds or other visual things they want to follow. A tip button gives advice about signs of infection.   | <b>Experiences:</b> Appreciate the possibility to compare wound pictures. One mother had technical issues.<br><b>Request:</b> To use phone gallery.   | It was very nice that there was a nurse who remembered that it was wise to have a picture for comparison from the hospital" M2  | <b>Experiences:</b> Value the opportunity to compare wounds. Explains what to look for in a sufficient way.<br><b>Requested:</b> None.   | "I think it is a very nice tool if used. You may see improvement or possibly a deterioration" N5   | Add completion in discharge function.   |
| <b>Weight:</b> Weight may be plotted and weight gain is calculated to be sufficient or not and visualised by a red cross or green checkmark.  | <b>Experiences:</b> Used by all caregivers. Appreciates the confirmation of good weight gain.   | "... I think that it was pretty good when you got such a green checkmark. It was kind of a relief, to see that things worked as they should" M7   | <b>Experiences:</b> No specific comments   |  | None.   |
| <b>Information:</b> Parents receive individualised information based on   | <b>Experiences:</b> Relevant, available, and easy to understand.  | "Both her great-grandmother, who has worked forty years in  | <b>Experiences:</b> More available in HOBS than in handouts.   | "I'm very happy that, it's now on the app, not in those binders" N3  | Personalise headlines in  |

Table 2. (Continued)

|   |  |   |  |   |  |
|---|--|---|--|---|--|
| an algorithm from “My child” in a reading list.   | <b>Requested:</b><br>Parents missed information about: Sick siblings, exercise after operation.  | the hospital, and the young lady at eight, got the same information and thought the information was fair” M8  | Possibility to gather written information is absent.<br><b>Requested:</b> None.  | “... the binder comes in handy when they are more than three months, because when they come to surgery number three, the binder follows the kid” N2   | information categories.<br>Add information as requested.                                   |
| <b>Summary:</b> Measures of condition are presented as bar chart and other measurements in curves.  | <b>Experiences:</b> Not interested in curves, but numbers from normal appearance.<br><b>Request:</b> Possible to delete results.   | “I only did it once, the week he was restless and unhappy. I counted how much he was breathing. He had same number as before - it was good” M1  | <b>Experiences:</b> No experience of use.  |   | Possible to delete results in curves and diagram.  |
| <b>Contact:</b> Parents may gather telephone number to local contact during hospitalisation. Information about who to call when is added to each service level. | <b>Experience:</b> Used in many different ways, but most important to gather number and information at one place.<br><b>Request:</b> None.                                       | “I have used it every time I needed numbers for all those we are going to call. I have entered all those numbers we put in the app before we left” F11<br>“It is okay to have everything in one place really” M2  | <b>Experiences:</b> Important information to receive. Traffic light makes it visual as more or less acute. Adds valuable information about who to call when.<br><b>Requested:</b> Add tip on important information in emergency calls. | “It is very nice that there is both contact information but also about when they should contact the different units” N7<br>“I think, they can be quite stressed if the child gets pretty bad at home in a way. It is very nice that things are easily accessible if they are entered” N5  | Include important information in emergency calls.<br>Add completion in discharge function. |
| <b>Overall impression</b>   | <b>Experience:</b> Easy, helpful, and available tool.<br>Not an everyday app.  | “It is a practical tool, instead of the binder. Everything is gathered at one place and the telephone is with us at all times” M11<br>“It was written inside the app, use if you are unsure of something. It is not such an everyday app, so therefore I used it when I was a little unsure of something, and to read something” M1 | <b>Experiences:</b> More available and forward-looking.<br>Specific heart disease focus makes it to something else than an “everyday app,” which is good.<br>Not all parents and health care workers are fond of apps.                 | “I think that by having it on the phone, it might be used more, and you never forget to take your phone with you when you go to hospital” N6<br>“It’s very good with the app... honestly, I’ve been sceptical all the way, thinking back on how overwhelming it would have been to have one sick child and then learn this as well. Instinctively, I could only wish to just be a mom and call if there was something I was wondering” N8 | Maintain written information as a possibility.<br>Let parents choose what features to use. |
| <b>New functions</b>  | <b>Requests:</b> A notebook for recording events and questions.<br>A timeline/calendar to record consultations.<br>Automatic sharing adaptation and measurements with a partner. |   | <b>Requested:</b> An interactive checklist for discharge teaching may systemise and clarify tasks to learn.  |   | Interactive discharge function based on My child.  |



aims to increase parents' awareness of their infant's normal (habitual) condition, help them assess signs of deterioration, decide who and when to contact for health services if necessary, and what to report. Heart OBServation was well received by parents and nurses in this usability study. The feasibility and benefits of this application in clinical practice will be investigated in further studies.

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